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Holistic Needs of University Students with Invisible Disabilities: A Qualitative Study

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Abstract

Aim—To inform rehabilitation professionals' role in supporting transition to higher education through identification and description of disability-related needs experienced by university students.

Methods—Participants were recruited from a large research-intensive university in the southeastern United States and included 13 students eligible for university disability services, 9 university personnel, and 1 parent of a university student with a disability. Disabilities of study participants were invisible; all but one chose to disclose diagnostic information. Data from 15 individual interviews and 2 focus groups were analyzed for themes.

Results—The Navigating Parallel Demands theme elucidates the ways disability-related needs extended beyond the classroom to areas of health and wellness, social and daily living. Navigation in Context describes personal and environmental circumstances surrounding processes used to meet a broad-range of demands.

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Author Contributions

All authors jointly conceived and implemented this study, contributed extensively to the work presented in this paper, discussed the results and implications, and contributed conceptualizations to the manuscript. C.K. wrote the main paper and co-authors provided editorial assistance and comment on the manuscript at all stages.

Declaration of Interests

The authors declare that there are no conflicts of interest.

Conclusion—University participation requires students with disabilities to navigate and manage a wide range of demands while securing appropriate supports. Findings inform rehabilitation professionals in providing anticipatory guidance when preparing students with invisible disabilities for post-secondary educational transitions.

Keywords

transitions to adulthood; qualitative research; invisible disability; participation; self-advocacy; postsecondary transitions

Enrolling in higher education presents important opportunities for development, discovery and improving the prospects of obtaining satisfying employment and financial independence. For individuals with disabilities, higher education offers especially important prospects for advancing employment opportunities while increasing options for broader social and community involvement (Newman et al., 2011). Across the United States, approximately 10% of all undergraduate and graduate students report having a disability, with over 70% of these students reporting disabilities such as learning, attention, psychiatric or chronic health impairments (Raue and Lewis, 2011). Within the research literature such impairments are characterized as invisible disabilities, indicating that the disability is not readily observable and that the choice to disclose the disability remains the individual's (Matthews and Harrington, 2000).

Upon graduation from high school to college or a university, the responsibility to identify as a student with a disability, and then actively seek-out required supports, is abruptly shifted from the school to the student (Madaus and Shaw, 2004; Skinner, 2004). Under the Individuals with Disabilities Education Act, in combination with the civil rights law Section 504 of the Rehabilitation Act, legal responsibility is placed on the primary and secondary schools for identifying needs and providing students with disability-related supports (Madaus and Shaw, 2004). Services and supports received in primary and secondary education may not adequately prepare students with disabilities to address issues with transition to post-secondary education. Parents, professionals and school officials negotiate and plan needed supports, with many students operating as passive recipients of needed accommodations. In contrast, under the Americans with Disabilities Act and Section 504, institutions of higher education only provide reasonable accommodations when requested by the student.

Despite availability of campus disability support offices, students with disabilities, as a whole, experience inferior outcomes when compared to post-secondary students without disabilities (Frieden, 2004; Stodden, et al., 2001). For students with disabilities, persistence and success in post-secondary education has been linked to the presence of, and access to, adequate and appropriate supports and accommodations (Garrison-Wade and Lehmann; 2009; Horn et al., 1999; Stodden et al., 2001). These include important non-academic supports such as mentorship, assistance liaising with student organizations, and social support received by on-campus individuals concerned with the student's well-being (MacLeod & Green, 2009). Students with disabilities must come to the university prepared

and determined to actively seek out and effectively advocate for the full range of needed supports, including those needed to succeed outside the classroom.

Students with disabilities face a broad range of barriers to successful post-secondary educational transition and full collegiate participation (Hart et al., 2004; Megivern et al., 2003). Participation, as defined by the World Health Organization (2001), is an individual's involvement in life's situations. For students and individuals with disabilities, the ability to participate in the range of life's experiences is tantamount to health, functioning and well-being (World Health Organization, 2001). While in the post-secondary classroom, full participation involves asking questions, completing course assignments, solving problems with peers, and engaging in critical and reflective discourse with instructors and classmates. However, collegiate participation extends beyond the classroom to encompass involvement in a diverse range of cultural, social, interpersonal and developmental experiences. Participation within the broader post-secondary educational experience ranges from developing lifelong personal relationships, cultivating professional ties and engaging in campus activities, to setting up and managing daily life and personal care routines.

The objective of this research was to expand understanding of the broad range of disability-related experiences and needs of university students with disabilities for the purpose of informing rehabilitation practice in supporting preparation for and transition to post-secondary education. This research examined both academic and holistic, or beyond the classroom, disability-related experiences of university students with invisible disabilities from multiple perspectives.

Methods

Because little is known about the broader holistic needs experienced by university students with disabilities, we used an exploratory qualitative research approach with thematic analysis of individual interviews and focus groups. Research strategies were drawn from phenomenological approaches in describing the experiences of students with invisible disabilities (Creswell, 2002). The study was approved by the sponsoring institution's ethics board. Written informed consent was obtained from each participant prior to data collection.

Recruitment and Participants

Participants were recruited from a large research-intensive university in the southeastern United States. Recruitment flyers, word of mouth and email announcements sent via campus listserv email lists were utilized in study recruitment of students and parents of students who were eligible to register with the university disability office and university personnel with who work with students with disabilities and have disability expertise or experience. Participants were 13 students, one parent of an undergraduate student registered with the university disability office and nine university personnel. Five participants had multiple roles within the university; three students spoke of additional experiences as an instructor at the university and two university personnel discussed experiences as both faculty and parents assisting a young family member with a disability through the university. During the interviews, 12 of 13 students disclosed their disabling condition with the 13th student sharing the nature of the disability without disclosing diagnostic information. Additionally,

both university personnel with parent-related experiences and the parent participant (collectively referred to as “parent participants” hereafter) disclosed the disabling conditions of their student. All disabling conditions represented in the study resulted in invisible disabilities (Table 1). The study sample was 62% female. Student participants included traditional and non-traditional aged undergraduate and graduate students.

Procedure

Research team members had clinical backgrounds in occupational therapy (1st and 2nd author) and rehabilitation nursing (3rd author). Eight PhD students from a variety of health-related disciplines who were enrolled in a qualitative field methods class assisted with data collection and preliminary data analysis. They conducted the individual interviews, focus groups and preliminary data analysis as part of the course, with data analysis led by an experienced qualitative rehabilitation nurse researcher (3rd author) and a rehabilitation science PhD student with training in qualitative research methods (1st author).

Face-to-face individual interviews and focus groups were conducted in community and campus locations using written interview guides designed to inquire about disability-related campus experiences. Two interview guides were prepared; one for university personnel (Table 2) and one for students (Table 3), which included adaptations for use with parent participants. Each interview guide was used for both the individual interviews and focus groups. For example, the university personnel guide was used for both the individual interviews and the university personnel focus group. University personnel who also had experience as a parent of a university student with a disability were individually interviewed using questions and probes from both prepared guides.

The prepared guides served as the starting point for semi-structured discussion, which allowed individual interview and focus group respondents to lead the dialogue to salient topics rather than constraining discussion to questions and probes created by study researchers. For instance, if a participant began to expand on a topic not included on the prepared guide, researchers encouraged the discussion of the new topic. In total, 15 semi-structured individual interviews, one student focus group and one university personnel focus group were conducted. Individual interviews lasted between 40 – 60 minutes; focus groups lasted 90 minutes and included four participants each. Responses to questions from focus group and individual interviews had several similarities with focus groups providing varied perspectives within the discussion and more emotion-laden information. All interviews and focus groups were audio-recorded. Field notes were recorded to capture immediate impressions of each interview and focus group.

Data Analysis

Audio-recordings were transcribed verbatim. Researchers used thematic analysis to interpret the data (Sandelowski and Barroso, 2003). Initial analysis consisted of reading and rereading interview transcripts and coding the narratives using open coding, whereby participants' words were used as the initial coding labels. Research team members then began to group similar codes, which were then regrouped and consolidated into subthemes and then themes

(Ryan & Bernard, 2003). Figure 1 depicts an example of the process used to consolidate codes into themes.

Throughout the data analysis process, research team members met in small groups to discuss the coding schemes, identify themes, and compare the codes and themes within and across transcripts and perspectives, exploring for similarities and differences. As questions about codes and themes were raised, the team went back to the transcripts and conducted focused coding to further clarify and refine the themes. Field notes were referred to and research memos were constructed for the purpose of recording and refining analytic thought processes of the team members. As themes were identified they were also checked with subsequent study participants, a step known as “member checking” (Guba & Lincoln, 1989). The systematic approach to data collection and analysis and the inclusion of multiple perspectives, both in the interviews and on the research team, help to enhance the trustworthiness of the study design and interpretations.

Results

Navigating Parallel Demands and *Navigating in Context* emerged as primary themes of this study. Participants spoke of a wide breadth of concerns and demands related to being students with invisible disabilities. Study participants described processes and contexts of managing demands and accessing supports associated with academics, health, social and daily-life. Parallels were described in managing academics and health and wellness. Additional parallels were described with regards to tasks and skills needed for accessing academic, health and social supports. Students managed demands and accessed supports within the context of the university's social, cultural and institutional environment and their individual needs, symptoms, past experiences, knowledge and skillset. Figure 2 illustrates the parallel nature of academic and health or wellness demands embedded within the personal, social and institutional context of university life as conveyed by study participants.

Navigating Parallel Demands

We use the term navigation to refer to actions taken in direction-finding or steering the course as a university student. The theme *Navigating Parallel Demands* highlights the analogous nature of the processes and undertakings related to *managing* and *accessing* supports relative to academic and health or wellness concerns.

Managing—Student and parent participants described added complexities in managing academic, health, social and daily life demands brought about by the student's disability-related health condition, symptoms and needs. Students voiced concerns regarding keeping up with classes, finding time for involvement in campus life, and mastering organizational and time management skills. Disability-related constraints, such as attention, organizational or processing challenges, made assignment completion more time-consuming. “Every written assignment takes me way longer than average.” [student 1] “They give you time and a half for the exam, but they don't give you extra time for homework.” [student 2]

Participants also spoke of interpersonal and disability-related difficulties with cooperative assignments and group classroom activities, especially when required to self-select into

groups. The process of negotiating small group membership and then negotiating the division of labor within the group was particularly stressful for some students. Students worried that the group may move too quickly or gloss over areas that needed to be understood in more depth. Students also experienced stress by having to work harder in order to keep up with group expectations. One participant, whose impairment resulted in slower processing and slower task completion, described the added pressure of feeling as if he must work extra hard on group projects: "...I don't want to slow anyone down...you remember who works hard, and I don't want to be one of the people that doesn't work hard because then no one's going to work with me." [student 3]

Living with an invisible disability also meant having to find ways to manage facets of their condition not readily considered by faculty, administration and student services (e.g. disability-related considerations regarding living situations) and thus, not well supported by existing campus support systems. "It's one thing to have academic help, but everything that affects you in school affects you in your daily life too." [student 1] While campus counseling services were readily available, participants felt as if there were fewer supports for dealing with their more basic day-to-day demands. "I have to pick and choose because I have a [disability/health] priority. I cannot have everything done because I have no energy to do it." [student 4] Participants voiced frustration with what they perceived as a disproportionate emphasis on classroom supports, with far less support or understanding for disability-related difficulties in prioritizing and managing organizational aspects of health, domestic and/or social demands associated with the university student role. Some students relied on nearby family to assist; others found ways to cope with support from friends and roommates. "Now a lot of these things are what normal college kids have trouble with, but his was heightened [because of his disability]." [university personnel 2/parent role]

Participants discussed the importance of learning how to create and maintain living spaces, daily schedules, and dietary and health routines appropriate for managing their particular symptoms or health condition. Managing aspects of their disability required the students to demonstrate insight about the impact of their symptoms and needs on their functioning inside and outside the classroom. Additionally, students needed insight and ingenuity to devise and implement coping strategies. One student spoke of how riding a crowded bus would over-stimulate her, leaving her agitated and anxious, and thus, unable to focus in class. This student learned that she must build in a significant amount of extra travel time prior to exams to give herself enough time to avoid over-crowded buses or time for recovery from over-stimulation before the start of the exam. For student participants, managing their disability-related needs meant that managing daily routines was made more complicated by considerations brought about from their diagnostic condition. Several students discussed the ways in which disability-related demands inhibited their social participation in campus life; social engagements were often prioritized after health-related needs. "My [disability] definitely prevents me reaching out." [student 4]

Accessing Academic Supports—Prevalent in all interviews was the concept of accessing needed supports. Negotiating the breadth of needed supports was a key component for success expressed by participants. All participants recognized the focal role of disability services in advocacy and support for classroom accommodations. The existence of a campus

disability center was unknown to some students until they were already having academic difficulties. For some, the disability services connection happened at the recommendation of a faculty member or student health professionals (e.g. campus infirmary). For others, connection with disability services came through family members or a classmate.

[Classmate] said, 'So you have [diagnosis] too?' And I was like, how did you know?... She was the one that told me to go to the [disability] service center, which I knew existed; but I'm like, if it's standing out that much, I probably need to go.
[student 1]

While institutions of higher education are required to provide reasonable accommodations for students with disabilities, the students are tasked with seeking out and negotiating these supports. As described by a university personnel participant:

I think one of the biggest things that is missing in that transition from high school to college is some way to get to these kids to teach them how to self-advocate. By the time they get to college nobody should have to hold their hands; but they also need to be taught that you've got to ask for what you want and what you need. A lot of times they will get in [to college] and they will just expect the professor is going to say something to them or ... approach them about whatever [the disability need] might be." [university personnel 2]

In order to receive classroom accommodations, students must bring clinical or psycho-educational documentation to the campus disability office to determine eligibility and necessary accommodations. The student must then present a letter to each instructor identifying needed classroom accommodations. Letters do not disclose reasons for the accommodations, or provide guidance for implementation. Students must be prepared to discuss their needs in constructive ways. Missing from the narratives were stories of instructor interactions where the student assisted the instructor in understanding how to best adjust classroom practices to meet the student's needs. Rather, many students felt they had to disclose their condition or share confidential health information in order to justify their needed accommodations. "I think the hardest part of that process is going to the teachers and explaining... trying to not tell them what the disability is but letting them know what's going on." [student 2] Several students reported strategizing as to when they would invoke their academic accommodations. For example, some students chose to forgo accommodations rather than negotiate them with instructors. Students also spoke of purposefully challenging themselves to cope without academic accommodations as a way of preparing to enter a workforce in which they expected no accommodations.

Healthcare and Social Supports—Several students relayed stories of grappling with trying to figure out how their symptoms might manifest within the classroom and what their diagnosis meant within the context of demands associated with university life. Students identified people within the university and/or their hometown community healthcare systems as important sources of support. They described disclosing intimate aspects of their lives to their health practitioners who were viewed as being supportive without being judgmental.

Really it was the [health practitioner] who knew inside and out what I was dealing with... It was like 'I can't believe you're doing this. You're amazing!' ... They were saying 'wow, you do have challenges, but you're rising above them.' [student 6]

Embedded in the healthcare system is the understanding that difficulties in the classroom can stem from physiologic roots.

Participants recognized the importance of support beyond classroom assistance. "It's nice having the right kind of support around me, [this includes] my family and all the right doctors." [student 1] Students also spoke of the importance of social support and acceptance received from good friends and understanding classmates who did not judge, or who provided small assistances, when disability-related issues arose within the context of their social or academic activities. Students relied on support from parents, romantic partners, roommates, good friends, caring classmates, caring instructors and health practitioners in managing the multiple layers of complexity experienced as a university student with an invisible disability.

Navigating in Context

The theme Navigating in Context describes circumstances and processes students encountered when managing academic and health demands, as well as accessing academic and health supports. Disability identity and perceived stigma impacted students' ability to garner supports necessary for success in managing academic and health demands.

Disability Identity—While understanding one's self and one's diagnostically-related constraints were integral to accessing and managing needed disability-related supports, many spoke of struggle in coming to terms with having an identity associated with a disability. Students relayed stories of their difficulty in understanding what specifics of their diagnosis meant within the context of their lives as a student. Students spoke of how the process of developing their own disability identity affected self-management of their disability-related needs. Several chose to forgo legally afforded accommodations because of not really believing their disability status or difficulty accepting that they needed additional supports to remain academically successful at the university level. "I got into [the university] on equal footing and equal position." [student 4] Students also spoke of being able to rationally understand their disability while continuing to have difficulty emotionally accepting it. "...[Disability professional] says I should consider [an accommodation]. But I'm not ready yet...I just have to be ready before I ask for the next set of services." [student 1]

In grappling with understanding their disability, students discussed struggling with knowing when to seek accommodations. Students spoke of their desire to succeed in the classroom without academic accommodations whenever possible. "You at the beginning are like, 'I am going to do this [without accommodations], let's see how the first test is.' And then...[I] didn't do well." [student 6] In figuring out whether or not she could cope without accessing her academic accommodations, one student described the condemnation received from the instructor when she presented her accommodation letter late in the semester.

He made me feel inferior...he yelled at me...I didn't say this, but I am thinking... 'I know I chose to come in late and I am sorry, but I thought I could do this without it and now I realize I can't.' [student 6]

Understanding and accepting personal strengths and disability-related constraints were pivotal to the student's ability to develop effective advocacy and self-management skills important for garnering needed supports.

Stigma—Threaded throughout the interviews were sentiments of the stigma felt from instructors and other students. Students described feeling resentment or a sense of unfairness regarding their needed academic accommodations. "The faculty and [other] students almost hold it against me because I am getting special treatment. They can't see disabilities so they don't see something broken..." [student 4] As conveyed from another student,

They [instructors] complain about the extra work they now have to do. Like getting proctors, or simple requests for posting presentations early enough for us folks with disabilities to prepare. ...Why make me feel different or sneaky or less of a student? [student 7]

Instructors spoke of having to contend with questions from students without disabilities about accommodations provided. In the process of accessing and managing supports, students with invisible disabilities had to find ways to cope with unsympathetic or disbelieving instructors and peers, unwarranted stigma, difficulty explaining needed accommodations, and pressures related to disclosure of private health information in order to help others understand the need for academic accommodations.

Discussion

This exploratory qualitative research sought to deepen understanding of the range of disability-related needs experienced by students with disabilities enrolled at a large university for the purpose of informing rehabilitation practice. Participants explicated experiences, roles and expectations related to academic, social and daily life. University students with invisible disabilities encounter a broad range of demands associated with managing needs and accessing supports when viewed from the holistic university experience. Decisions to pursue needed supports are impacted by others' disbelief regarding the presence of an actual disability, perceived stigma and sense of unfairness from instructors and peers. Decisions to pursue supports are also influenced by the student's understanding of symptoms and self-perceptions of disability-related needs. Understanding holistic post-secondary educational experiences provides essential information for rehabilitation professionals who are working with youth transitioning to a university. Rehabilitation professionals are important sources of anticipatory guidance for individuals with disabilities; they just need to know what types of situations and challenges to prepare students for. Findings explicated academic and holistic needs, demands, roles and contexts associated with university participation of students with invisible disabilities that can be used to augment anticipatory guidance.

University students with invisible disabilities need a range of competencies and skills to access supports and manage demands in the areas of academics, health and wellness, campus and social participation, and daily living. Findings shed light on disability identity and relational challenges associated with negotiating classroom accommodations. These challenges were exacerbated by experiences of stigma and a sense of unfairness surrounding classroom accommodations. While all university students must cope with a wide range of demands, disability-related concerns introduced an added complexity to the tasks students had to manage. Rehabilitation professionals are ideally situated to assist university-bound youth, or transitioning young adults with invisible disabilities, to meet the range of organizational and interpersonal university demands made more complicated by having a disability.

Self-Determination

Development of self-determination is a critical factor in a student's academic success and ability to fully participate in post-secondary education (Garrison-Wade and Lehmann, 2009; Olney et al., 2004). Descriptions of students grappling with their desire to forgo, or minimally invoke, classroom accommodations (often with detrimental results) clearly illustrated the interrelated nature of the students' needs for autonomy, belonging, and a sense of competence within the university classroom. These descriptions are notable in light of theoretical understandings of self-determination, which posits that satisfying a person's needs for competence, relatedness and autonomy are essential to optimal functioning and development at all life stages (Deci & Ryan, 2012). Our findings point to areas of individual competence and social relatedness that rehabilitation professionals can focus on when working to facilitate the self-determination of their university-bound or transitioning clients with invisible disabilities.

Implications for Rehabilitation Professionals

Skills related to self-determination and self-advocacy are important for rehabilitation professionals to address when working with university-bound youth with disabilities. In order to support successful transitions for students with disabilities, self-determination and self-advocacy training should encompass facilitation of self-management of academic, health and wellness, social and daily life activities (e.g. budgeting time, determining priorities) within the context of managing collegiate and disability-related demands. For most students, the transition from high school to university involves an expansion of student responsibilities and the adoption of new young-adult activities and roles. In concurrence with the children and youth version of World Health Organization's International Classification of Functioning, Disability and Health (2007), preparation for post-secondary academic transitions must extend beyond preparation to meet academic and basic self-care demands; it must expand to include preparation to meet the broad range of organizational and interpersonal demands associated with engaging in activities across the breadth of campus settings (e.g. shared housing, student groups, student services, classrooms). Rehabilitation efforts must include a focus on developing the higher-level skills needed for academic, health, social-relational, and daily living self-management demanded of university students. Examples of such higher-level skills include critical appraisal of novel campus situations and the creation of prioritized and feasible action plans and schedules.

Moreover, rehabilitation professionals can play a key role in helping youth growing up with invisible disabilities understand their personal abilities, strengths and disability-related difficulties. These understandings are important first steps in helping the youth identify and understand their needs, and then advocate for them. Rehabilitation professionals can aid university-bound youth in identifying and prioritizing disability-related needs within anticipated university classroom, social and daily life contexts. It is also important for rehabilitation professionals to teach the youth how to seek out, discriminate, negotiate and utilize relevant supports. For study participants, disability-related self-management began with establishing deep understanding of their specific health condition and how symptoms manifested within the range of university experiences. It was through deepening understanding of the health condition that student participants began to understand which supports worked best and why, when supports were most needed, where they might go to seek out supports, and then how to effectively advocate for their provision.

Holistic Transition Planning

Client-centered practices, which focus on addressing the individual strengths and needs most salient to the transitioning student, are consistent with fundamental aspects of transition planning and self-advocacy practices used within the education system (e.g. Kohler's Taxonomy for Transition Planning [Kohler, 1996]). In order to bolster preparedness for the breadth and complexity of university demands, rehabilitation professionals and educators, at all levels, must work collaboratively to ensure that broader holistic needs (e.g. understanding diagnostically related symptoms, health management) of university-bound youth with disabilities are addressed (Cobb and Alwekk, 2009; Gil, 2007). Beyond collaboration, cross-disciplinary support coordination and research are needed to better understand and address the complicated and interrelated nature of academic and health transitions (Repetto et al., 2012; Repetto et al., 2013).

This study identified parallels in the types of demands and processes associated with managing academic and health or wellness needs. Findings suggest that strategies and skills used to meet demands in one domain may have generalizability to the other. For example, skills related to seeking out supports for academic accommodations may have parallels to skills needed to seeking out health providers or supportive professionals on campus. However, continued research is needed to develop and test innovative rehabilitation approaches for supporting successful academic and health transitions and full collegiate participation of youth and young adults with invisible disabilities.

Limitations

The exploratory nature of this study, sample size, inclusion of a broad range of health conditions, and sampling from one university limit generalizability of study findings. While study findings suggest a duality of needs (academic and health) experienced by university students with invisible disabilities, additional research is needed to understand which needs may be universal across, or unique to, specific health conditions, symptoms or levels of severity, as well as various campus environment conditions. Additionally, the large majority of study participants (87%) identified as non-Hispanic white. Because experiences of disability are socially driven, racially and ethnically experienced disability differences are

certainly possible and should be further explored. Including faculty and staff who have disability training or experience is a bias of this study. However, because we were seeking depth of insight into the needs of students with invisible disabilities on the university campus, we pursued those who had spent time contemplating and living the issues being investigated. Perspectives from participating faculty and staff verified student perspectives.

Conclusion

University students with invisible disabilities must work through disability-related self-advocacy and self-management tasks in handling broad-range demands and accessing needed supports in the areas of academics, health, social and daily life. Students navigate multifaceted demands against the background of the university's infrastructure (e.g. physical environment, services) and socio-cultural environment (e.g. faculty and classmates' attitudes), whose impact ranged from decisions to pursue needed academic supports, to choices regarding living spaces, social engagement and organization of daily routines. Physical and occupational therapists working with academically successful adolescents and young adults with invisible disabilities are ideally situated to work with the youth, their families, and secondary school educators in preparing students for the broad range of challenges associated with being a university student with an invisible disability.

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Figure 1.
Example of process used to identify themes from initial code labels.

Figure 2.

Process and context of managing academics and health demands and accessing academic and health supports.

Table 1

Description of Study Participants.

Disclosed disabling conditions of student participants and student family members	Age range of undergraduate student participants (number of students)	Age range of graduate student participants (number of students)	University personnel participant positions (number of personnel)	Age range of university personnel participants (number of personnel)
Attention deficit	18-25 years (4)	18-25 years (2)	Academic Faculty (4)	26-39 years (3)
Auditory processing disorder	26-39 years (1)	26-39 years (1)	Academic Administrator (1)	40-52 years (2)
Autism spectrum	40-52 years (1)	40-52 years (3)	Student Services Faculty (2)	53 years (4)
Cystic fibrosis		53 years (1)	Student Services Administrator (1)	
Learning disability			Student Services Staff (1)	
Low vision				
Traumatic brain injury				
Attention deficit + autoimmune disorder				
Learning disability + autoimmune disorder + low hearing				
Learning disability + sensory processing disorder				

Table 2

University personnel individual interview and focus group guide.

Interview and focus group questions and probes for university personnel

1. Talk about your experiences when working with and interacting with students with disability?
 - (a) What types of disabilities have students in your classes had?
 - (b) How does your work environment (e.g. workload; organizational structure; policies) influence working with students with disabilities? Can you give me an example?
 - (c) What kinds of experiences have you had with regard to University structures and practices that promote involvement of students with disability?
 - (d) What are your experiences with policies or practices that facilitate the safety and inclusion of students with disability?
 - (e) What, if any, university conditions (e.g. attitudes, structures, practices) do you feel fosters a sense of full membership in the university community for students with disability?
 - (f) What conditions do you feel might hinder it?
 2. What do you do or have observed being done (or policy implemented) that you feel enhances student learning especially for students with disabilities?
 - (a) Campus life?
 - (b) Satisfaction of the student w/ disability?
 - (c) Overall student success?
 - (d) What detracts?
 3. Please tell me about one of your most positive experiences at the university related to students with disability.
 4. Now please tell us about one of your most disheartening experiences at the university related to students with disability. What could have been done to have prevented or rectified the experience?
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Table 3

Student and parent individual interview and focus group guide.

Student and Parent Interview/Focus Group Guide

1. Tell us (me) a little about how you [your child] chose to come to the university?
 - (a) What was it like when you first came to the university?
 - (b) How is it different now?
 2. How did the disability related services provided by the university influence the decision to come here?
 - (a) Have you [your child] used any disability related services provided by the university?
 - (b) How are the services working for you [your child]? Please tell me about the experiences [or why not?].
 - (c) What/how did you [your child] learn about the services used?
 - (d) What made you [your child] decide to use or not use the services available?
 - (e) Does the university provide the services you [your child] need?
 - (f) What do you wish you [your child] used more of?
 3. What have academic experiences been like?
 - (a) What are experiences in disclosing disability status to instructors or other university faculty or staff member?
 - (b) Talk a little about classroom and testing experiences.
 - (c) What about doing homework and group assignments?
 - (d) What are experiences related to participation in research projects or presentations?
 - (e) Do you [your child] have any experiences regarding competing for funding? What are they like?
 4. Talk about what campus life is [has been] like?
 - (a) What are experiences regarding participation in campus life activities?
 - (b) What is it like when you participate in on-campus or university sponsored social or club activity?
 - (c) Sporting events?
 - (d) Fraternities/sororities?
 - (e) Dining?
 5. What are experiences regarding mentorship at the university?
 6. Can you tell me about an experience that fostered a sense of belonging (full membership) within the university community?
 7. Can you tell me about any experiences that caused you [your child] to feel distanced or reduced a sense of belonging to the university community?
 8. Can you please tell me about one of the most positive experiences at the university related to your [your child's] disability?
 9. Now please tell us about one of the most disheartening experiences at the university related to disability. What could have been done to have prevented or rectified the experience?
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